Making a difference

The impact of health and care research in Wales

October 2020
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Research matters
Why we do health and care research and what it means to people

This report showcases the health and care research being undertaken in Wales and how it impacts on improving health and social care services, making the lives of patients and communities better. Our simple aim is to give you an insight into the way researchers set about tackling real-world problems which often profoundly affect thousands or even millions of people, and how their work can translate into concrete benefits for them and for society.

In selecting eight case studies, in addition to the extensive research taking place into COVID-19, we were truly spoilt for choice. In the current extraordinary circumstances of the pandemic we had to include the work that is being done to develop and test treatments and to research vaccines which will be able to protect people from getting the disease. But we also wanted to feature a wide range of examples, some very cutting edge and others quite everyday but just as important.

They are all linked by two key features. First, they are work done by research teams in Wales, across our universities and the NHS and care system. Second, they are all examples of real impact, for people in Wales and further afield.

Often the research done here in Wales bears dividends for the whole of the UK, and internationally. We can be very proud of that – while at the same time recognising that our health and care system in Wales needs to be making good use not just of research done here in Wales but of the UK and international research effort.

Health and Care Research Wales is supported by Welsh Government and exists to ensure that today’s research makes a real difference to tomorrow’s care. Formally, our mission is:

To promote, support and provide oversight of health and care research in Wales to ensure it is of the highest international scientific quality, is relevant to the needs and challenges of health and care in Wales, and makes a difference to policy and practice in ways that improve the lives of patients, people and communities in Wales.

This means we need to work with a wide range of stakeholders – health boards, local authorities, patient and public groups, universities, third sector organisations, government agencies in Wales and the UK, and others besides.

It isn’t complicated, though it can sometimes seem so. Our job is to try to get the funding, the organisation, and the delivery of research aligned so that projects like the ones featured in this report can proceed, and their findings can be used to shape policy and practice.

Fundamentally, I think people who have spent their careers in health research do it because they want to make a difference. They want their ideas, their research, and their endeavour to end up improving the lives of patients, their families and the communities and populations we serve. And this report shows how health and care research can really make a difference.
COVID-19 pandemic highlights impact of Welsh research collaboration

If ever there was a doubt that research matters, coronavirus has put the search for a cure to the front and centre of all our minds.

From the start of the pandemic, Wales has played a key role in the UK-wide effort to find treatments for COVID-19 through research, with Welsh researchers contributing to multiple and complex studies. As well as having a major influence in the search for a vaccine, the impact in Wales has been driven by the collaborations that have taken place across a wide range of institutions, professions and cultures.

Studies set up through Health and Care Research Wales and coordinated nationally are ongoing right across NHS Wales, looking into multiple treatments for patients, identifying risk factors and specific genes for susceptibility, as well as strengthening the evidence for a vaccine.

Since March 2020, Health and Care Research Wales has prioritised resources and fast-track support for COVID-19 urgent public health research, and is also working with UK counterparts to enable Welsh researchers to access funding for research.

Professor Kieran Walshe, Director of Health and Care Research Wales said: “This pandemic has been a grim reminder of the value of health research – finding treatments, developing vaccines and stopping the spread of COVID-19 have all relied on a fantastic research effort in Wales and across the UK.

“The collaboration between universities, health boards, researchers and Welsh Government as well as colleagues in the other nations has been unprecedented. The way everyone has worked together, at speed, and under incredible pressure has been nothing short of outstanding. The lessons learned in this pandemic about how to do great health research at pace and scale will be a force for driving forward our future research and development programme in Wales.”
Wales plays key role in vaccine trials

Coordinated by Health and Care Research Wales, in May 2020 a collaboration (between Public Health Wales, Aneurin Bevan University Health Board and the Centre for Trials Research at Cardiff University) took part in the phase 3 vaccine trial sponsored by the University of Oxford and funded by Coalition for Epidemic Preparedness Innovations (CEPI) UK Research and Innovation.

Public Health Wales led the recruitment of 500 participants within Aneurin Bevan University Health Board for the Oxford Vaccine Group COVID-19 vaccine trial. The aim is to find a safe vaccine that will develop immunity against the virus and thus prevent the disease.

Dr Chris Williams, Principal Investigator for Public Health Wales and lead for the vaccine trial in Wales, said: “This is an important study to test the effectiveness of one of the main candidate vaccines for COVID-19 in Wales. If successful, vaccination will provide a route out of this pandemic. We will be recruiting participants for screening and administration of vaccine, and monitoring outcomes and safety.”

At the time of going to print more than 250,000 people across the UK had signed up for future COVID-19 vaccine trials through the NHS COVID-19 vaccine research registry. Preparation was also underway for multiple new vaccine trials to be set up across Wales as part of a national trial delivery programme.

Antibodies from recovered patients could be used in the frontline of treatment

Antibodies from patients who have recovered from COVID-19 are now being trialled as a possible treatment in two urgent public health research studies in Wales. It’s hoped the antibodies, contained within plasma collected from people who have already had COVID-19, could help people who are critically ill in hospital with the disease.

Non-COVID-19 plasma has been used daily in NHS Wales for a variety of needs for many years. It’s hoped COVID-19 convalescent plasma therapy will help patients develop immunity as it transfuses antibodies against the virus, helping the patient who receives the plasma to fight infection.

The COVID-19 convalescent plasma collection programme is being delivered in Wales through the Welsh Blood Service, Welsh Government and Public Health Wales.

Dr Matt Morgan, Health and Care Research Wales Specialty Lead for Critical Care, and Consultant in Intensive Care Medicine at the University Hospital of Wales, said: “This involves giving the antibodies from patients in Wales who have already recovered from COVID-19 to patients who are critically ill. Much like giving blood, patients who recover can donate their antibodies in the form of plasma to help with the trials and hopefully help patients.”

“We still need more evidence-based, effective treatments for COVID-19. Although breathing machines and some drugs may help whilst staff care for patients as best they can, we really need more treatments that work. These studies aim to answer the question of whether using antibodies from patients who have recovered can save the lives of patients with COVID-19.”

Convalescent plasma, is being included in the RECOVERY and REMAP-CAP studies, alongside other drugs already being trialled.

The Randomised Evaluation of COVID Therapy (RECOVERY) trial is testing to see if existing or new drugs can help patients who have been admitted to hospital with confirmed COVID-19. It’s the world’s largest randomised clinical trial of potential COVID-19 treatments, led by the University of Oxford and funded by the Medical Research Council.

REMAP-CAP: a platform trial for severely ill patients with COVID-19, led in the UK by Imperial College London and funded by the University Medical Centre Utrecht, is testing multiple treatments at the same time, for patients admitted to intensive care with severe community acquired pneumonia.

These UK-wide studies have been set up across Wales through Health and Care Research Wales and are demonstrating positive early results. The RECOVERY trial has released preliminary results showing low-cost dexamethasone reduces death by up to one third in hospitalised patients with severe respiratory complications of COVID-19.

Findings published in September 2020 show that corticosteroids to treat COVID-19 have reinforced evidence that outcomes for severely affected patients can be significantly improved by using these inexpensive and widely available drugs, with one paper suggesting the risk of death can be reduced by up to 20%.
GP from Wales leads UK-wide research study to find a potential treatment

A GP from Wales – who says he’s “one of the lucky ones” after battling coronavirus – is now leading a UK-wide research study to find a potential treatment. Professor Chris Butler, who works part time for Cwm Taf Morgannwg University Health Board, had severe symptoms, including a fever and cough, and was bedridden for 10 days.

Professor Butler is the Chief Investigator of the PRINCIPLE study. The study, which is led by the University of Oxford and set up in Wales through Health and Care Research Wales, is aiming to find treatments for older people that can help them recover quicker from coronavirus and stop them needing to go to hospital.

The study is set up in GP surgeries across Wales and is open to people aged 50 and over with serious health conditions, or over 65s, who currently have symptoms of coronavirus.

“The purpose of the trial is to identify treatments that could be widely and safely used in primary care. It’s about taking the pressure off secondary care services, our hospitals, but also reducing the severity of complications for patients,” said Professor Butler.

Patients who volunteer will be allocated at random to take part in one of two arms of the study, either current standard treatment, or standard treatment plus a drug which is an experimental treatment for COVID-19 illness.

“It’s absolutely critical that we get information about treatments that can be used in primary care,” said Professor Butler.

“There are major trials taking place in hospitals with people who are already quite sick. Ours is a separate question. We’re asking whether treatment in the community can help people, who are managing symptoms earlier on in the disease, to recover more quickly so they don’t need to go to hospital.”

(Pictured) Professor Chris Butler
Could genetics provide the key to finding out who is most susceptible to COVID-19?

Thousands of people severely ill with COVID-19, including those currently or previously in an intensive care unit, will have their genetic code studied to help scientists understand whether a person’s genetics may influence their susceptibility to the virus.

Wales is taking part in a major new genetics study of COVID-19, led by the partnership between the GenOMICC Study Consortium (led by the University of Edinburgh) and Genomics England. The study, announced by the Secretary of State for Health and Social Care, Matt Hancock, on 13 May, will help us better understand the virus’ varied effects on people and support the search for treatments.

Researchers from the University of Edinburgh’s GenOMICC project will work together with Genomics England and over 170 NHS hospitals including those in Wales. Health and Care Research Wales is nationally coordinating study set up and recruitment in Aneurin Bevan, Cardiff and Vale, Cwm Taf Morgannwg, Swansea Bay, Betsi Cadwaladr and Hywel Dda University Health Boards. The study aims to sequence the genomes of 20,000 people who are severely ill with COVID-19. In Wales, 100 patients have been recruited to the GenOMICC study already.

The data collected by health boards in Wales and others will be compared to that from a further 15,000 COVID-19 patients who experienced only mild symptoms. This data will be collected from participants in the 100,000 Genomes Project and UK Biobank.

Professor Tamas Szakmany, Consultant in Adult Critical Care and Anaesthesia, Aneurin Bevan University Health Board said: “GenOMICC is a straightforward study to set up and recruit into with the help of local research and development teams and Health and Care Research Wales. I’d like to encourage every critical care unit in Wales to participate, so we can have important answers about the differences in genetic susceptibility for COVID-19 disease.”

Why data is a vital tool in the fight against COVID-19

The Secure Anonymised Information Linkage (SAIL) Databank, funded by Health and Care Research Wales, has been selected to play a key role in an international collaboration to accelerate COVID-19 research.

Established by Health Data Research UK and partners, following funding announced by the COVID-19 Therapeutics Accelerator and the Gates Foundation, the new International COVID-19 Data Research Alliance and Workbench will support the rapid development of therapies to combat the global effects of COVID-19.

Many organisations across the world are conducting studies into COVID-19 and generating data that, when pooled together and reanalysed, can lead to powerful insights that help accelerate the discovery of interventions. However, the data is often siloed, making it difficult for those generating the data to collaborate quickly.

The International COVID-19 Data Research Alliance and Workbench will provide an environment for focused collaborative research, matching high value data from many sources with cutting-edge analysis to accelerate collaboration, discovery and development of therapeutics to combat COVID-19, all with privacy and accessibility in mind.

The Health and Care Research Wales COVID-19 research in Wales webpage has details of all related research studies that are active, or in set up, in Wales.

Led from Swansea University Medical School, SAIL Databank is an internationally-recognised research group that works to anonymise and link routinely collected data from the NHS and other sources in a safe and secure way, for the purposes of supporting health and social care research.

SAIL Databank is the Trusted Research Environment for BREATHE, the Health Data Research UK hub for respiratory health, and is the focus for the accumulation of a wide range of COVID-19-related data. This includes managing access to de-identified data from the popular ZOE COVID-19 Symptom Study app.

Swansea University’s SAIL Databank team also bring their innovative SeRP (Secure e-Research Platform) technical platform to the alliance, delivering a novel adapter technology, lowering the technical bar for further data partners to join the alliance.

Professor David Ford, Director of SAIL Databank and SeRP (Secure eResearch Platform), and Chief Data Officer at BREATHE, said: “We are delighted that Swansea University’s Secure eResearch Platform (SeRP) is providing its adapter technology to this important collaboration. Working with Aridhia, we will deliver the means by which independent, well governed, data repositories can participate in large scale federated research studies enabled by the alliance, without having to move their data out from their local control.”

SAIL Databank has received funding from Welsh Government through Health and Care Research Wales and its predecessor organisations since 2006, which has provided a concrete foundation for their role in supporting COVID-19 research.
Research into a new drug treatment for women with the most common type of incurable breast cancer is one of the biggest Welsh-led breakthroughs and has the potential to improve millions of lives around the world.

Scientists in Cardiff have discovered that using a new combination of drugs is much better at shrinking tumours and controls the growth for twice as long a previous treatments.

Breast cancer is the most common type of cancer in the world, with 55,000 new cases each year in the UK alone, so the research offers hope that the new treatment could become the standard of care offered to patients worldwide.

The findings of the trial, called FAKTION, which was led by Velindre Cancer Centre and Cardiff University, have been published in The Lancet Oncology and presented at the world’s biggest cancer conference, The American Society of Clinical Oncology, in Chicago.

Dr Robert Jones, Consultant Oncologist and Chief Investigator for the research, said, “The results of the trial were quite remarkable with the new drug treatment doubling the amount of time a patient could expect to have their cancer controlled.

“Our trial results were reviewed by The American Society of Clinical Oncology who decided it was one of the most important pieces of cancer research to have been reported in the world last year.

“The level of patient benefit seen is remarkable and hasn’t occurred for any cancer research led from Wales in the last five years. It has the potential to prolong the lives of millions of patients across the world.”

THE TEAM BEHIND THE RESEARCH

Thanks to the team that made it happen: Sarah Townsend Head of R&D, Velindre NHS Trust; Robert Jones, Reader and Consultant in Medical Oncology, Velindre NHS Trust and Cardiff University; Angela Casbard, Senior Research Fellow, Centre for Trials Research, Cardiff University; Angela Carucci, Senior Trial Manager, Centre for Trials Research, Cardiff University; Jill Halpin, Research Nurse, Velindre Cancer Centre and Tracie Madden, Senior Trial Manager, Centre for Trials Research, Cardiff University.

(Pictured) Dr Robert Jones with patient Susan Cunningham
The work began when a small group of scientists and doctors from the Centre for Trials Research at Cardiff University, and Velindre NHS Trust, analysed current approaches to treating patients with breast cancer to see where possible improvements could be made.

It was decided to target cancers that can respond to hormone therapy — called oestrogen receptor positive breast cancers — which account for around 75% of new breast cancer cases in the UK each year.

Although such cancers can respond well to hormone therapy they all eventually become resistant, and so the strategy focused on what makes the cancer resistant and how to combat this.

One particular protein - AKT - is seen to drive this resistance so it was about using a new drug Capivasertib to try to neutralise the AKT combined with the hormone treatment, called Fulvestrant.

These drugs had never been combined before so the aim was to see if they could be given safely together and if it led to better results than hormone treatment alone.

The trial, which was led by Velindre Cancer Centre and Cardiff University, began in 2015 with a small number of patients to check it was safe to use the drugs together.

Once this was confirmed it was widened to 140 patients from 19 hospitals across the UK. Half of the patients received the two drugs in combination and half received the hormone treatment in combination with a placebo.

The results showed that 41% of patients getting the new combination saw a significant shrinkage in their cancer — shrinking to 70% or smaller of its original size — compared to only 12% for those in the placebo trial.

Patients who received the combination also managed to have their cancer controlled more than twice as long as others in a placebo trial – an average of 10.3 months compared to an average of 4.8 months without the same treatment.

The current trial data also suggests that patients treated with the new combination live for an average of six months longer.

The trial is now entering phase 3 involving 700 patients from around 170 different hospitals worldwide, to see if further positive results are recorded.

If they are, the team believes it will become the standard treatment of care for incurable breast cancer patients around the world.

Dr Jones added: “When you’re given a diagnosis of cancer that is incurable, any extension of life is incredibly important and it’s extremely pleasing to see the potential benefit this has for patients.

With further testing it’s now entirely possible that this new treatment will become the standard of care for breast cancer worldwide.

“To be part of research of this impact is why I go to work and it’s so exciting to think that millions of patients around the world could have their lives improved from this breakthrough.”

The trial was sponsored by Velindre University NHS Trust, coordinated by the Centre for Trials Research at Cardiff University, and funded by Astra Zeneca, Cancer Research UK and Velindre Charitable Funds.

PATIENT STORY

Retired doctor Susan Cunningham from Cardiff joined the trial in 2017 after she discovered her breast cancer, which she was first diagnosed with in 2005, had spread and was incurable.

She said, “I was doing very well until three years ago when I was diagnosed with metastatic bone cancer. I’d only just retired and was diagnosed within a month, so it was life changing, our all our plans had to change and it was difficult.

“Being on a trial has given me great hope for the future. It’s meant that I have been relatively well for the past three years. If it gives you more time and there’s more advances in medicine due to trials like this, then it can give you more of an extension - and quality of life as well.

“Initially I thought I wasn’t going to see my grandchildren but now I have hope that I am going to survive for a lot longer and see my family grow.”

FACT FILE

According to the most recent figures from the Welsh Cancer Intelligence and Surveillance Unit:

- More than 8,600 women in Wales got breast cancer over a three-year period, way ahead of any other type of cancer
- This has risen from 156 cases per 100,000 women in the three years to 177.5 cases per 100,000 (2013-2015)
- 93.2% of women diagnosed at stage three survive a year - and around 64% at stage four
Treating post traumatic stress disorder with an innovative eight week online programme

Cardiff team develops online guided self-help programme for post traumatic stress disorder (PTSD) which is effective and is now in national and international guidelines

An online guided self-help programme to treat PTSD has made such a positive impact it has contributed to international guidelines as a recommended way of helping people with the condition.

The Spring programme was developed in partnership by the Traumatic Stress Research Group at Cardiff University and clinicians at Cardiff and Vale University Health Board following lengthy research to find ways to increase access and availability of treatment for people with PTSD.

PTSD is a common mental health condition that is triggered by a traumatic event such as an accident or assault. It affects around four million people in the UK and causes symptoms including flashbacks, nightmares, avoidance of situations that link back to the event and poor quality of life.

Most people with PTSD require specialist treatment and support from a therapist but waiting times in the NHS are long, often 18 months or over, and there is difficulty accessing services.

A new way of providing help was needed so researchers developed a self-help programme based on trauma focused cognitive behavioural therapy that could be accessed online at home and is supported by regular guidance meetings with a therapist.

It provides an eight week step by step treatment that helps overcome traumatic stress symptoms and improve health and wellbeing.

The approach has been so successful that, globally, guided self-help is now recommended as routine treatment for people with PTSD and is included in two key guideline documents; the International Society for Traumatic Stress Studies (ISTSS) and the National Institute for Health and Care Excellence (NICE).

Dr Neil Roberts, Consultant Clinical Psychologist at Cardiff and Vale University Health Board and Honorary Senior Research Fellow at Cardiff University, has been involved in the research for ten years.

He said, “Working as a psychologist in mental health I know how scarce resources are and how big the need for help. It can be difficult for service users to get appropriate treatment quickly and easily, so potentially this can make a big impact.

“We know that lots of people are very motivated to engage with this approach. It contains the same components of standard face to face treatment but can be accessed flexibly, at a time that is convenient to patients, in the privacy of their own home.”

THE TEAM BEHIND THE RESEARCH

Thank you to the team that made it happen; Chief Investigators at the Traumatic Stress Research Group at Cardiff University, Professor Jon Bisson, Dr Catrin Lewis, Consultant Clinical Psychologist, Dr Neil Roberts and therapists Dr Neil Kitchiner, Dr Tracey Vick, Dr Julie Dorey, Dr Jane Boyd, Dr Clare Crole Rees and Dr Mat Hoskins.
It also makes a big difference to a therapist’s time, reducing waiting lists and is helpful to people who live in remote areas and have difficulties accessing treatment.

It’s heartening to see that both the NICE and ISTSS guidelines recognise that guided self-help has an important role to play, provides a beneficial approach and increases the options of help available.

The programme was tested during its development phase on 19 participants who were suffering from mild to moderate PTSD and then underwent further testing by the research team at Cardiff University and clinicians from Cardiff and Vale University Health Board Traumatic Stress Service in a pilot randomised controlled trial (RCT) with 42 participants, with very positive outcomes.

The trial also found that the programme helped to reduce the average amount of time clinicians spent with patients from around 12 hours to 2.5 hours. This enables more patients to be seen.

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The trial also found that the programme helped to reduce the average amount of time clinicians spent with patients from around 12 hours to 2.5 hours. This enables more patients to be seen.

The National Institute for Health Research (NIHR) then funded a further RCT study called RAPID to test the programme against the gold standard of individual face to face therapy, to see how they compare.

The multi-site trial involves 196 participants from across South Wales, Manchester, London and Lothian who signed up in December 2019.

The final follow up of RAPID participants will take place in January 2021, with finalisation of the research expected in March 2021.

Professor Jon Bisson, Chief Investigator at the Traumatic Stress Research Group at Cardiff University and Chair of the ISTSS Treatment Guideline Committee, said the work is likely to have a significant impact on the care of PTSD sufferers around the world and make an important contribution to future research.

He said, “There is enough evidence to recommend therapist guided internet based intervention using trauma focused cognitive behaviour therapy approaches for the treatment of PTSD.

“PTSD is a treatable condition. We don’t suggest that symptoms will improve overnight but with regular use of the programme there is every chance of recovery.”

NIHR was the funder for the RAPID study and Cardiff University is the sponsor.

PATIENT FEEDBACK

A member of the RAPID patient and public involvement group, who used Spring as a participant in research before the RAPID trial, said the programme was ‘empowering’.

She said, “Embarking on a guided self-help programme gave me the control I needed. It was empowering. I’d had enough of being a victim.”

“The programme allowed me to become desensitised to what I’d experienced. You don’t suppress it but you’re able to step away from the memories and then deal with them.

“I’ve realised that in the time it would have taken me to be on a therapist’s waiting list I was already back to being me. I would recommend this programme to anyone in a similar situation.”
A breakthrough into the use of blended diets for children with complex health needs has led to a change in practice and policy in Wales and across the UK.

Interest in giving home blended diets instead of, or in addition to, commercial feeds to children who need a feeding tube has been growing, however there were no studies in the UK addressing the risks and benefits.

Feeding tubes are used in the management of numerous clinical conditions including neurological disorders such as cerebral palsy, problems with swallowing or digestive disorders such as intestinal failure.

In each Health Board area around 200 children and young people are likely to need support in this way.

Families often reported that they were unable to enjoy active lives as their children experienced severe diarrhoea and vomiting from commercially prepared formula. This caused weight loss and made it difficult to leave the home impacting on their general health and wellbeing.

Many families were turning to health care professionals to ask for support with using blended diets which their children were able to better tolerate, leading to less tummy upsets and the ability to lead more sociable lives.

However from a clinical point of view, there were concerns about the safety of this approach including worries that a blended diet could lead to tube blockages, increased risk of infection and contamination.

When a parent approached Consultant Nurse, Sian Thomas, to inform her that they had been giving their child a blended diet and needed the health board’s support to continue, she decided to undertake a research study to explore the risks and benefits to influence clinical practice.

“When I was approached by a parent who was already using a blended diet with her child but needed support to continue doing this, I knew that a robust investigation was needed to ensure we could provide clear professional guidance.”

Sian began by working closely with the family who had approached her to support a child with complex needs to attend a mainstream school and was able to change clinical policy for the individual to enable the blended diet to continue.

This innovative work generated interest from other health boards in Wales and its impact was acknowledged when Sian was awarded the title of Royal College of Nursing Wales Nurse of the Year 2016.

The next step was to expand the research so Sian decided to undertake a multi-centre study to examine the benefits and risks from a parental perspective for children who are fed by tube and are already receiving a blended diet in comparison to children who are receiving a standard commercial feed.

She was supported by a clinical reference group comprising of a Paediatric Gastroenterologist, Clinical Nurse Specialist and Professor in Human Microbiome.

She was also awarded a Research Building Capacity Collaboration First into Research Fellowship funded via Health and Care Research Wales. This enabled Sian to be supervised by an experienced researcher from the University of South Wales.

The 18 month study, sponsored by Aneurin Bevan UHB involved 52 children aged two -16 years from five university health boards in Wales; Aneurin Bevan, Cardiff and Vale, Cwm Taf Morgannwg, Swansea Bay and Hywel Dda.
Parents were offered a choice to attend a routine clinic or carry it out at home and Sian met with all parents to complete a survey detailing their experience. The theme for the questions were identified from the issues and risks identified by healthcare practitioners.

The findings were positive, with all participants who received a blended diet expressing significant benefits including a better toleration of the feed, with episodes of vomiting much lower for children on a blended diet compared to those on a commercial feed.

There was no increase in complications in tube blockages or infection rates and a significant improvement in the prevalence of bowel problems.

Parents also reported an improvement in the child’s mood and behaviour, weight gain, and a better toleration of medication which led to a reduction in convulsions and hospital admissions.

The results of the study contributed to a change in the British Dietetic Association policy in December 2019 and has changed practice nationally. It has been supported by Welsh Government and adopted by all seven health boards in Wales.

Sian said, "It has been really beneficial to develop the evidence base in this area and this has influenced innovation in clinical practice, locally and nationally. The findings from the study have enabled the development of local guidance and have informed the revision of national policy and practice as well as potentially opening the door for further research in this area."

Most importantly however the work has empowered patients and their families, and improved their quality of life. They are able to eat the same food, socialise and have support from professionals to make a choice.

As well as informing national policy change, Sian’s work has also been presented at a number of major conferences including the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), the Royal College of Paediatrics and Child Health (RCPCH), and the British Dietetic Association.

The next steps now are to extend the option of blended diets for adults in both a hospital and community setting.

The National Institute for Health Research, Welsh Government, Wellcome Trust, British Society of Gastroenterology and MRC all contributed support for the programme of research.

PATIENT STORY

The family of the first child to receive a blended diet via a tube in Aneurin Bevan University Health Board said the impact was ‘like a light being switched on’. Their daughter, Saffron had complex health needs and significant feeding issues. She suffered continuous vomiting and diarrhoea from the commercial feed and was failing to thrive.

“She was uncomfortable and it was an extremely difficult time because we couldn’t see how our little girl was ever going to be able to go to playgroup or school because the symptoms were so severe,” said her mum.

“We transitioned to the blended diet over a month and almost immediately she was better. The vomiting stopped, the pain went away and she was able to sleep through the night. It was like a light switched on, she became interested in things and has thrived.

“She is gaining weight nicely and has managed to go to school. Feeding is no longer an issue for us and that’s just amazing.”
The result of a trial to understand the best temperature to cool the body in intensive care following a cardiac arrest has changed clinical practice worldwide and improved the care of patients.

Therapeutic hypothermia had long been recommended by international guidelines but evidence to support its use was limited and the temperature associated with the best outcome was unknown.

An international trial led in the UK by researchers at the University Hospital of Wales (UHW), Cardiff compared the impact of cooling patients down (often with pads and cold water) to a temperature of 36°C against 33°C. The normal body temperature is 37.5°C.

The results of the Targeted Temperature Management (TTM) trial showed that the less aggressive cooling to 36°C was equally as effective as 33°C.

This change has been adopted into international resuscitation guidelines and changed clinical practice in a number of countries.

Dr Matt Morgan, Consultant in Intensive Care Medicine at UHW, said, “It was thought that rapid cooling could protect the brain after someone suffers a cardiac arrest but it was uncertain which temperature was best to use and how beneficial the process is to the patient.

“The results of the trial were a surprise to many as it showed that there was no difference to cooling patients down to a warmer temperature. “This has improved care as if you take the body temperature down to 33 this can cause shivering which takes energy and oxygen from someone who is already fighting to recover from cardiac arrest.”

Thank you to the team that made it happen: Dr Matt Wise, Critical Care Consultant; Dr Matt Morgan, Consultant in Intensive Care Medicine; and Critical Care Nurses Jade Cole, Nikki Palmer, Jenny Brooks, Chris Williams, Jacqueline Curtin and Stephen Fernandez. Most of all, thank you to the patients and their families.

In addition to study support from Cardiff and Vale University Health Board, Dr Matt Wise was supported by a Health and Care Research Wales NHS Research Time Award.

(Pictured) Dr Matt Morgan (centre), and critical care nurses Matt Wise (left) and Jade Cole (right)
The impact of health and care research in Wales
Making a difference

There are around 2,800 out-of-hospital cardiac arrests in Wales each year (according to the British Heart Foundation) and around one million individuals suffer a cardiac arrest annually in Europe alone. Unconscious survivors of out-of-hospital cardiac arrest have a high risk of death and can suffer poor neurological outcomes.

The TTM multi-centre international trial took place from 2010 to 2013, led in the UK by Dr Matt Wise, and involved 950 patients who were admitted to intensive care in an unconscious condition after their heart had been restarted by CPR (cardio-pulmonary resuscitation) following a cardiac arrest.

The Cardiff team, working with five other hospitals across the UK, recruited the third highest number of patients amongst the ten countries taking part.

The results were published in the New England Journal of Medicine and the research is amongst the top 1% of its cited papers.

In October 2015, a number of international resuscitation societies updated their resuscitation guidelines. This includes the European Resuscitation Council, the American Heart Association and the Resuscitation Council UK.

The impact on clinical practice has continued to grow with a significant number of intensive care units having changed their temperature management following the TTM trial.

In the UK around half of all intensive care units now have a target temperature of 36°C. This change is mirrored in around one third of units in Denmark, Sweden, Iceland, Norway and Finland and around one quarter of units in Holland.

The most recent assessment of the impact on practice up to January 2015 encompassed 264 intensive care units in 11 countries with 37% declaring a change in temperature management.

To date, 50 additional papers about the work have also been published in peer-reviewed journals.

Research is now continuing with a second trial led by UHW in the UK with nine UK hospitals and 1,900 patients worldwide.

One of the concerns of the first trial was that both 33°C and 36°C were too cool so TTM2 is comparing 33°C with a normal body temperature of 37.5°C.

Half of patients are cooled down to a temperature of 33°C for 24 hours, as well as getting all the usual life-saving treatment. The other half are kept at 37.5°C - but not allowed to get hot either.

The trial will then look at how many patients survived 180 days and how good their recovery was at two months and two years.

Dr Morgan hopes they will find out if the approach really is beneficial. He said, “This research is already making a big difference in a number of ways. From a clinical point of view it’s vital to make research more common and acceptable in critical care and to involve wider services in the hospital to deliver it.

The active man, who works for a sportswear company, did not know he had a blocked artery.

When Andrew was admitted to the University Hospital of Wales, he was sedated and included in the trial. He spent two weeks in hospital and had a further four months off work.

He said, “I’m fine now, back to my normal work and playing football with my son but you realise it can be taken away in an instant.”

Only 10% of patients who need resuscitating outside hospital every year after a cardiac arrest ever recover and leave hospital. Andrew Barnett is one of the lucky ones.

Around 18 months ago, the 46 year old collapsed and his heart stopped beating as he played football with his young son at Eastern Leisure Centre in Llanrumney. Luckily the centre had a defibrillator and the manager was able to administer CPR, reviving Andrew.

One challenge the trial does present however is over consent, as in intensive care people are often unconscious and their family traumatised. UHW has a specialist recruitment team on hand 24/7 who will approach patients or families about the trial later, not wanting to upset a family in a very stressful situation, she said.

“Fundamentally though, it’s all about improving a patient’s chances of good survival and recovery. When someone had a cardiac arrest it used to be considered the end. Now for every ten people who go to hospital five will walk out alive and two will even go back to work.”

Jade Cole, lead critical research nurse, said patient safety and family wishes are a priority. “The family can veto what the patient would want because we don’t want to upset a family in a very stressful situation,” she said.

“I’ve done it hundreds of times but I’ve never had a patient unhappy about being involved in a research study - they have always been positive.”

Wales has contributed 54 patients to the trial so far and the results will be published in January 2021.

Dr Matt Wise added “The risk of not conducting studies like this is that we’ll carry on giving suboptimal or incorrect therapy to many patients.

“I remember talking at a conference in Brussels and someone at the end asked me: If you have a cardiac arrest what temperature would you want to be? I answered - I’d want to be in the trial.”

“Patent Story”

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Physiotherapy in Huntington’s disease

Global research led by Cardiff University shows the impact of physiotherapy in patients with Huntington’s disease

Research led by a team from Cardiff University has shown that physiotherapy can make a big difference to the management of symptoms and quality of life for people with Huntington’s disease (HD).

Huntington’s affects between six and 13 people in every 100,000 and is a genetic condition that damages nerve cells in the brain affecting movement, memory and behaviour.

There is currently no cure for the disease but after more than a decade of collaborative, global research, the Cardiff Huntington’s Disease Group has produced good evidence for the role that physiotherapy can play in helping people to improve their fitness, motor function, balance and gait.

The work has led to the publication of the first ever evidence based clinical guidance for the management of physiotherapy for Huntington’s. These internationally recognised guidelines were published by the Journal for Neurology in February this year.

Professor Monica Busse, Director of Mind, Brain and Neuroscience Trials in the Centre for Trials Research, Cardiff University, said, “The impact of Huntington’s disease is devastating and I’m always humbled by how people and families go through life living with the condition and how positive they are in dealing with the associated challenges that they are faced with.

“When we realised (in 2007) that there was no formal guidance in place for physiotherapists working with people with HD, we knew that we had to start at the very beginning. Initially, we wanted to understand what was important to people with Huntington’s and explore the views of physiotherapists as to how to impact on those problems.

“Everything we learned in those initial studies guided our ongoing programme of research starting with the development of a framework for physiotherapist practice and the first research evaluations that quantified increased risk of falls and clinical muscle weakness.”

The group went on to conduct collaborative studies with colleagues in England, Scotland, the Netherlands, Finland, Spain, Germany, and the USA.

This helped to define the problems experienced by people with HD in ways that could be reliably measured and to develop and evaluate targeted physiotherapy approaches relevant to each stage of the disease.

The Cardiff studies have informed the globally recognised physiotherapy clinical guidance and led to the development of several resources to help both health care professionals and people with Huntington’s realise the benefits of physiotherapy and regular physical activity.

This includes the ‘Move to Exercise’ video which enables people to exercise at home.

The video is being used across the world and has been translated into several languages including Chinese, Arabic, Spanish, Portuguese and Italian.

The team are also invited contributors to the bi-annual Huntington’s Disease Association of England and Wales accredited course for health professionals, where they focus on training health professionals to have a conversation with Huntington’s patients about physical activity and how to develop an individual plan that meets their needs.

The course has been attended by more than 150 health professionals since it launched three years ago and has helped to raise awareness and understanding of the benefits physiotherapy can make.
The impact of health and care research in Wales

Making a difference

PATIENT IMPACT

Dr Una Jones, Senior Lecturer in Physiotherapy at Cardiff University and a member of the research team, said, “Everyone who has Huntington’s is affected differently so it’s really important for physiotherapists to talk to the patient and their families directly to find out what is most important to them.

“The more people can do in the early stages of the disease, the better the journey ahead and we know that regular exercise can help with movement and balance across the life-span of a patient, as well as improving mental health.”

Along with the clinical guidelines, the Cardiff research has led to the publication of 42 international peer reviewed publications papers and the team is continuing to lead globally with evaluations in exercise and rehabilitation.

Professor Busse said, “Whilst our research has already made a difference to many of those affected by this devastating disease, there’s still so much more to do to ensure people living with Huntington’s disease have access to physiotherapy and support for physical activity.

“We have learned a lot from our work with the Huntington’s disease community. We now need to apply some of our learning to the many people living with a rare neurological disease for whom physiotherapy and physical activity may be truly beneficial. We need to understand whether our guidance - or something similar - might be applied more widely.”

The sponsor for this study was Cardiff University and the research funders were: Health and Care Research Wales; Alzheimer’s Society; Jacques and Gloria Gossweiler Foundation; European Huntington’s Disease Network; Huntington’s Disease Society of England and Wales; Wellcome Trust Institutional Strategic Fund; Medical Research Council Confidence in Concept Scheme; Research Capacity Building Collaboration Wales; Paul Jeffries Waters Bequest Fund.

WHAT IS HUNTINGTON’S DISEASE?

Huntington’s disease is a condition that stops parts of the brain working properly over time. It’s caused by a faulty gene and is passed on (inherited) from a person’s parents. It gets gradually worse over time and is usually fatal after a period of up to 20 years. Both men and women can get it.

The symptoms, which usually start at 30 to 50 years of age, but can begin much earlier or later, include:

- difficulty concentrating, memory lapses and depression
- difficulty moving
- stumbling and clumsiness
- involuntary jerking or fidgety movements of the limbs and body
- mood swings and personality changes
- problems swallowing, speaking and breathing

The New Guidelines Recommend:

- Physiotherapy assessment and advice from the point of diagnosis
- A lifestyle that includes regular aerobic exercise, such as swimming, brisk walking, cycling or dance into each week
- A focus on improving or maintaining fitness early on, in combination with strength, balance and flexibility exercise
- Activities to help maintain independence in daily life (sitting down and standing up, or getting up safely from the floor in the event of a fall)
- Advice for caregivers to maintain involvement in physical activity as the disease progresses

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PATIENT IMPACT

There is one patient story which really resonates with Professor Busse. She said, “There was a lady who needed two people a day to care for her, she couldn’t get to the bathroom on her own and she was very depressed.

“After a relatively short period of targeted physiotherapy, she was able to walk the short distance to the bus stop with one carer to meet her daughter as she came home from school. The difference this made to her wellbeing was amazing and encapsulates why physiotherapy is vital to improving the quality of life for people with Huntington’s disease.”
HAPPEN network reaches 13,000 children

A primary school health network led by researchers at Swansea University is helping to improve the health and wellbeing of children across Wales.

HAPPEN (Health and Attainment of Pupils in a Primary Education Network) was developed with children and teachers in 2015 to look at ways of supporting schools to meet the needs of their pupils in becoming healthier and happier.

Rather than concentrating solely on data and expert opinion on children’s health and wellbeing, the HAPPEN team decided to ask children themselves about their health and lifestyle, including what they would like to change to ensure their physical and mental health improved.

An online questionnaire was developed in partnership with pupils and schools to capture this information. It is then fed back to schools enabling them to identify needs and make informed decisions about the planning and provision of health and wellbeing in their local curriculum.

To date more than 300 primary schools from every local authority area in Wales have taken part in the survey and over 13,000 pupils aged eight to 11 have contributed their views.

A further 200 schools across Wales have registered to take part this year and with the new curriculum coming into place in 2022, this focus on health and wellbeing has never been more important.

Professor Sinead Brophy, Director, National Centre for Population Health and Wellbeing Research at Swansea University, who is part of the team leading the research said, “Research shows that healthier and happier children do better in school and education is an important determinant of future health.

“There is a need for learning experiences that simultaneously improve health, wellbeing and engagement, whilst addressing curriculum needs.

“The school setting offers an opportunity to deliver a curriculum that engages children to reach their potential and define their future health outcomes as well as reducing inequalities.”

The HAPPEN survey asks children to answer 30 questions about a range of health behaviours and wellbeing for example, do they eat breakfast, and if yes, what do they eat; how much exercise do they have in a week, their life satisfaction and what would they change to improve how they are feeling.

The data is then collated and compiled into a report within four weeks which the school can then use to develop action plans to prioritise health and wellbeing activities in line with the new curriculum. The survey was initially piloted in Swansea, working closely with the local authority’s sport development team, and around 20-30 schools took part during 2015.

It was then extended to schools in the Bridgend area before eventually being rolled out across Wales, with involvement from the regional education consortia.

THE TEAM BEHIND THE RESEARCH

Thank you to the National Centre for Population Health and Wellbeing Research team that made it happen: Professor Sinead Brophy, Director; Emily Marchant, Child Health and Education Researcher; Charlotte Todd, Wellbeing Lead; Sarah Toomey, Communications & Engagement Officer; and Michaela James, Physical Activity Lead.

(Pictured left to right) Professor Sinead Brophy, Michaela James, Dr Emily Marchant and Charlotte Todd
Participation has increased from around 1,000 pupils in 2015 to more than 13,000 by 2020, with numbers set to increase further.

Catherine Barnett, Headteacher of Eveswell and Somerton Primary Schools in Newport, South Wales, whose schools took part in the survey, said that the HAPPEN initiative is beneficial to pupils both physically and mentally.

She said, "We are pleased to be part of HAPPEN and value its support and expertise. It gives you pointers to develop the curriculum in a different way. You can take into account pupils’ views very easily because you know what they think and it’s made our curriculum even more focused on health and wellbeing in a bespoke way."

As well as helping schools to support children to become healthier and happier, HAPPEN also acts as a platform for a number of research projects and evaluations of school based programmes in Wales.

This includes quantitative analysis of curriculum based outdoor learning programmes and an evaluation of the Daily Mile scheme in Wales, which involves children running loops of a playground or school playing field for 15 minutes every day.

The work looked at the impact being made on children’s fitness in Wales and the need to reduce inequalities.

The results of the research showed the positive impact of outdoor activities and the Daily Mile in improving fitness and wellbeing of all children, regardless of whether they lived in a poorer or wealthier area.

A number of recommendations to improve delivery of the Daily Mile were identified and shared nationally, including with Welsh Government to help inform future policy.

The network team has had support from the Economic Social Research Council (ECRC), work with the Administrative Data Wales (ADW) and are part of the National Centre for Population Health and Wellbeing Research (funded by Health and Care Research Wales).

The team is carrying out ongoing research to link the data it has collated with anonymous information held in the SAIL (Secure Anonymised Information Linkage) Databank. This contains routinely collected data about health and education and enables the team to carry out a wide range of research including examining the factors associated with low educational attainment and poor wellbeing in children.

Emily Marchant, Child Health and Education Researcher, National Centre for Population Health and Wellbeing Research, said, "We are encouraging schools to use HAPPEN as a needs analysis to identify areas to prioritise with curriculum activity. It’s pupil focused and provides a unique opportunity to ensure activities are even more focused on health and wellbeing, meeting the needs of the children."

"The data we collect enables us to pick up early predictors for trends across Wales ensuring we can inform future policy development and most importantly ensure our young people live happy and healthy lives."

The research carried out by HAPPEN has been shared on the world stage, including the World Health Organisation Healthy Cities conference in Belfast and the 5th European Conference on School Health Promotion in Moscow.

It has been included in the Chief Medical Officer for Wales’ Annual Report and was shortlisted for the Research and Innovation Awards at Swansea University in 2018.

A number of research articles have also been published which have received more than 40,000 visits.

For more feedback from schools visit here www.happen-wales.co.uk/what-schools-say-about-happen/
Over three years, two separate but interlinked studies have looked at the impact of paying dentists differently and whether dental care professionals, such as hygienists, can manage low risk patients as well as a dentist.

The results of the research, which was funded through the National Institute for Health Research (NIHR) Health Services and Delivery Research Programme, have also led to the creation of the first ever faculty for dental care professionals and are influencing the NHS dental contract reform process in Wales.

The first research study was led by the North Wales Organisation for Randomised Trials in Health (NWORTH) Clinical Trials Unit at Bangor University and focused on an NHS pilot project that was taking place in Northern Ireland, looking at the possibility of changing dental contract policy and paying dentists differently for one year.

Dentists are usually paid by ‘fee for service’, which means they are paid for the number of treatments carried out. For one year however, it was decided to pay dentists by capitation, which means a fixed income, usually based on the number of patients in a dental practice.

More than 30,000 NHS patients and 34 NHS dentists took part in the study from eleven practices, which looked at whether the change in payment affected the quantity of care delivered, the type of treatment undertaken and the cost of providing NHS dental care for the Northern Ireland Government.

The team compared data from the year before the change was made, the year of the change to capitation, and the year after the change, when dentists reverted back to fee for service.

The study showed that there was a significant drop in patterns of care and activity levels such as extractions, fillings and scale and polishes, during the capitation year but that this came back to pre-pilot levels once the fee for service was reinstated. Patient numbers also reduced.

The fall in activity and patient throughput was calculated to cost over £11 million per annum for the Department of Health, Social Services and Public Safety, should the pilot NHS contract be rolled out across Northern Ireland. This is because the patient contribution to NHS dentistry would be lost to the system.

THE TEAM BEHIND THE RESEARCH

Many people were involved in supporting the two studies including NWORTH Clinical Trials Unit; Paul Brocklehurst, School of Health Sciences, Bangor University; Zoë Hoare, HT School of Health Sciences, Bangor University; Lynne Williams, HT School of Health Sciences, Bangor University; Philip Preshaw, HT Faculty of Dentistry, National University of Singapore; Karen Shepherd, HT PPI user-researcher; Martin Tickle, NI School of Dentistry, University of Manchester; Stephen Birch, NI Centre for Health Economics, University of Manchester; Ruth McDonald, NI Manchester Business School, University of Manchester; Tanya Walsh, NI School of Dentistry, University of Manchester.

(Pictured) Professor Paul Brocklehurst
The results of the study were shared widely in Wales and led the Chief Dental Officer for Wales to decide that a capitation payment system should not be pursued as part of NHS dental contract reform in Wales.

Paul Brocklehurst, Professor of Health Services Research and Deputy Chief Dental Officer for Wales, who led the research, said, “This study was incredibly interesting because although there was a big drop in activity levels by taking away the incentive to be paid for every treatment done, what we did discover was that dentists were actually able to do other valuable things.

“By having a fixed income the treadmill of dentistry decreased and dentists found they had more time to spend with patients and had more time to manage, develop and train their practice teams.

“So although the results of the study showed that paying dentists differently by capitation was not the answer, there were some elements that could be considered for future workforce development.”

The second study focused on whether dental hygienists could be as effective as dentists at undertaking check-ups for low-risk routine NHS dental patients and whether they could reduce the cost of service provision.

Currently, the use of dentists as front-line clinicians in NHS dental practices is costly, with over half of the 21.7 million check-ups undertaken each year in UK resulting in no further treatment.

The Bangor University team undertook a pilot study, this time across the North West of England, involving 217 low-risk adult NHS dental patients.

The group was split into two, with half of the patients cared for by dental hygienists and half by dentists, for a 15 month period.

The team also ran an evaluation alongside the study, interviewing the Chief Dental Officer for Wales, dental commissioners, dentists, hygienists and patients, to gain their views.

The results of the study showed that a dental hygienist could manage low-risk patients as well as a dentist, with no difference in levels of care provided.

It also found that the hygienists spent more time with NHS patients to discuss their needs and give health promotion advice.

The results of the research had a major impact on workforce planning and led the Chief Dental Officer for Wales to ask the research team to write a report for Welsh Government called ‘Training an oral health needs-based workforce for all (using all the talents)’ in 2017.

The Welsh Government is engaging in an NHS dental contract reform process, which started in 2018, in response to two key policy documents ‘Taking Oral Health Improvement and Dental Services Forward in Wales’ and ‘The Oral Health and Dental Services’ Response to A Healthier Wales’.

The key elements of the Welsh NHS dental contract reform are to: promote a preventive approach to care; extend the use of skill mix as part of prudent healthcare; provide care to new patients with higher needs; prompt ‘well patients’ to attend at longer intervals; and deliver high quality evidence-based care according to need.

The coronavirus pandemic led to a pause in the contract reform process which is rescheduled to start in Spring 2021.

This led to the subsequent commission of an All Wales Faculty for Dental Care Professionals (DCPs) which was led by Bangor University.

The faculty, which was officially launched earlier this year by Vaughan Gething, will be training dental hygienists and dental nurses to ensure demand can be met across Wales.

It will also ensure that DCPs are central to the ongoing contract reform process in Wales, which began in 2018.

The faculty, which is the first of its kind in the UK, is fully supported by Welsh Government, Health Education and Improvement Wales, and Public Health Wales.

It has also been endorsed by the General Dental Council, British Association of Dental Therapy, British Society for Dental Hygiene and Therapy, and the British Association of Dental Nurses.

Professor Brocklehurst added: “I went into research to make a difference and it’s great to see that these two projects have made a significant impact on both policy and practice in Wales.

“No other nation has created anything like the All Wales Faculty and not only will this improve the quality of training, it also ties in with the prudent healthcare approach by getting people to work their full scope of practice.

“This research will help to improve the provision of NHS dentistry in Wales, develop the future workforce, provide value for money and improve population health.”

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Nearly thirty years of research led by a team in Swansea University Medical School has significantly improved the way gastroenterology services are delivered and made a big difference to the quality of life for patients.

The programme of research has focused particularly on the care of patients with inflammatory bowel disease (IBD), a chronic condition that affects around 10 per 100,000 people in the UK and causes pain, diarrhoea and restrictions to daily life. IBD includes conditions like ulcerative colitis and Crohn’s disease.

The team, led by Professor John Williams, wanted to find ways to improve both the efficacy of care and the patient experience.

The work has made such an impact that it has changed the way patients access services and championed the role of nurses becoming specialist endoscopists in the UK and the USA.

Phedra Dodds was the first nurse recruited and trained in endoscopy at Neath General Hospital as part of the MINuET trial. The work had such an impact on her that she is now the Clinical Lead for National Endoscopy Programme for Wales and trains nurses in endoscopy throughout the UK.

“I am so proud of the work that has been done by Professor Williams and the team to improve services and care for patients in this area,” said Phedra, who is also an Honorary Lecturer in Medicine at Swansea University.

“I saw a big challenge to improve the way gastroenterology services and patient care were provided. Inflammatory bowel disease is such a debilitating condition that it can really impair the quality of life for those who suffer from it.

“We really wanted to make the service more patient orientated, to improve experience and outcomes, but knew we needed the evidence to drive change. So began this huge programme of work collecting detailed clinical data from trials and real life practice.”

The work began in the early 1990s when an academic team in Swansea University developed an electronic patient record and implemented it in the gastroenterology department at Neath General Hospital.

The analysis of the patient data collected demonstrated a relentlessly rising workload and unpredictable demand for inpatient and outpatient services, particularly in the care of patients with IBD.

The condition is often characterised by unexpected flare ups and the usual three month/six month follow up appointments did not correlate with the unpredictability of patient symptoms. It became clear that patients needed continuing access to care to ensure they could receive support and treatment when it was needed most.

Professor John Williams said, "We saw a big challenge to improve the way gastroenterology services and patient care were provided. Inflammatory bowel disease is such a debilitating condition that it can really impair the quality of life for those who suffer from it.

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The team decided to carry out a randomised controlled trial to evaluate the impact of providing patients with open access to the hospital department in place of routinely booked follow up appointments. The trial was run in Neath General Hospital and Morriston Hospital, Swansea.

The results demonstrated that this was safe and effective, and of value to both patients and professionals, with patients actually preferring it.

It was identified however that to work most effectively, a specialist nurse was needed to ensure a point of contact for patients. The nurse would be able to provide telephone support and triage, help with clinics and ensure rapid access to services at a time of need.

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It has generated more than 40 papers in high impact journals, including The Lancet, BMJ, Gut, Alimentary Pharmacology and Therapeutics, American Journal of Gastroenterology and the Journal of Crohn’s and Colitis.

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It was identified however that to work most effectively, a specialist nurse was needed to ensure a point of contact for patients. The nurse would be able to provide telephone support and triage, help with clinics and ensure rapid access to services at a time of need.
In order to enhance the attractiveness of the specialist nurse role, training in endoscopy was also offered, in the belief that there was a potential future for nurses undertaking endoscopy in place of doctors.

**Endoscopy** is a procedure where organs inside the body are looked at using an endoscope, a long thin tube that has a light and camera at one end. The research evidence in support of this role substitution was at that time limited to small observational studies, and with funding from the Health Technology Assessment programme, the clinical and cost-effectiveness of nurse delivered endoscopy was evaluated in a national, multicentre trial called MINuET (Multi-Institutional Nurse Endoscopy Trial).

The trial compared doctors with nurses performing endoscopy. The analysts of the data were not aware which professional had undertaken the procedure and the results showed that nurses were just as effective as doctors in finding abnormalities. Nurses made more complete records and patient satisfaction was generally better after a nurse-performed procedure.

Other benefits included less lists being cancelled and doctors’ time being freed up, enabling 40% more patients to be seen in the first year.

As a result of this evidence, it was accepted that nurses could be trained to become effective endoscopists and this thinking informed the development of this specialist role for nurses in both the UK and USA.

Following this work, the team was commissioned by the British Society of Gastroenterology to undertake a systematic review of the burden of gastroenterological disease in the UK, and the evidence base for current and future service delivery in this field.

This extensive review formed the basis of a new national framework for services in gastroenterology and hepatology by the British Society of Gastroenterology in 2007.

Further research has continued to inform the modernisation of services. The team has used linked routinely collected data to explore the risks of unplanned admission to hospital for IBD patients, the importance of timely surgical intervention and the outcome of emergency admission for upper gastrointestinal bleeding.

The evidence on the outcome of emergency admission for IBD helped to secure funding for a large multicentre trial comparing the clinical and cost effectiveness of two drugs in the treatment of acute severe colitis. This showed that although the two drugs were equally effective and safe, one was much cheaper – leading to a cost saving of £5,652 per patient over 30 months.

Overall, the findings have provided evidence that has:

- influenced the development of open access services for patients with IBD
- extended nursing roles in endoscopy in the UK and USA
- promoted more out-of-hours endoscopy across the UK
- confirmed the effectiveness of medical and surgical treatment in acute severe colitis

Professor Williams added: “Throughout all of this work, the focus has been on the patient and how we can improve their care, experience and outcome.

“We have demonstrated that developments in service delivery can be evidence based and that this evidence is key to driving change.”

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